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Home-making after stroke. A qualitative study among Dutch stroke survivors



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ABSTRACT

Stroke survivors may suffer from physical limitations as well as cognitive and behavioural difficulties. Many survivors work on their recovery in a rehabilitation clinic with the aim to return to their own home again. Since full recovery is often not feasible, they face the challenge of coming to terms with lasting effects of the stroke and of giving meaning to their home place again.

Based on in-depth interviews with stroke survivors, we discuss the meaning of the home with respect to changed post-stroke identities. Our findings show how, for many participants, a formerly comfortable home becomes a space of struggle. Formerly stable bodily routines become time-consuming and demanding, reciprocal relationships with significant others change, often becoming unbalanced dependence. In conclusion, each stroke survivor faces a different struggle to accommodate a changed self in a house that does not feel like home anymore. These findings imply that stroke rehabilitation services need to address the individual and everyday challenges that stroke survivors and their families face at home, to improve their sense of home and well-being.

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1. Introduction

Stroke survivors form a significant and increasing group in today's ageing society. In the Netherlands, one in twenty adults aged 50 years and over experiences a stroke and survives (CBS, 2014). A stroke is an illness with a sudden onset that affects physical, cognitive, and behavioural functioning (American Stroke Association, 2015). In the Netherlands, patients with suspected stroke are directly admitted to a acute stroke unit in a hospital for acute diagnosis and treatment. Survivors of stroke with moderate to severe disability, who need inpatient rehabilitation after completion of their acute treatment, then move to a stroke rehabilitation unit where they are treated by a specialist multidisciplinary team.

Although the multidisciplinary team works on optimal functional recovery in the clinical setting, most stroke survivors are confronted with changes in their body, identity and life course in the home setting (Ellis-Hill and Horn, 2000). Many survivors experience depression (Wood et al., 2010), social isolation (Salter et al., 2008), and reduced well-being (Achten et al., 2012) after returning home. Psychologists and social workers in the clinic do

anticipate the mental and social impact of post-stroke impairments after discharge, however, since the primary goal of stroke survivors is to gain optimal functional recovery, they tend to postpone thinking about potential lasting disabilities (Nanninga et al., 2014). This could be related to the conceptualization of home in rehabilitation medicine as a material, physical space, whereby home evaluations are an important step in discharge planning from inpatient to home settings (Drummond et al., 2013; Steultjens et al., 2013). During home visits, occupational therapists assess safety and recommend physical adaptations where necessary, such as installing wall-handles in the bathroom. Although such adaptations contribute to stroke survivors' independence, this neglects the idea that the home is also, and maybe first and foremost, a place that has meaning for its inhabitants, and that is part of their identities (Blunt, 2005).

In an earlier study, we looked at the meaning of place for stroke survivors, and discovered that different attachments, meanings and longings mark the stroke rehabilitation process in the whole chain of care (Nanninga et al., 2014). In the current article, we examine stroke survivors' and, to a smaller extent their family caregivers', experiences of home in more depth. This case study will provide insight into what provides stability and a sense of being anchored to the home, through zooming in to the experiences of people who have brusquely lost these anchors.

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2. Theoretical framework

In cultural geography and geographical gerontology, the home is conceptualized as a material as well as affective space, shaped by people's everyday practices, experiences, social relations, memories and emotions (Blunt, 2005). Central characteristics of the home are that it is a place over which people experience control, where they perform daily routines, which they decorate with objects that are meaningful to them, where they engage with significant others, and where they remember significant past events. As a result, it becomes a place where people feel they belong, and which can be a place of refuge from the outside world (see Chaudhury and Rowles, 2005; Peace et al., 2006; Rowles, 2000, 2008; Rowles and Bernard, 2013; Rowles and Watkins, 2003; Swenson, 1998). In line with this, it has been shown that experiences of home are an important dimension of well-being (Conradson, 2012; Wiles et al., 2012). Being such a central place, the home can thus become a positive place where people can 'be themselves', but also a place where people feel locked up against their will (Blunt and Dowling, 2006).

Home places are dynamic, negotiated, contested, contextual and complex processes. What 'home' is and means changes throughout the course of one's life. In later life, for instance, the role of the home may gradually transform from a basis for out-of-home activities to being the locus for every day practices (Sixsmith et al., 2014). At the same time, the home can also function as a 'portal' for imagined transportation to other people, places and times, as artefacts kept in the home may evoke memories of these (Rowles and Bernard, 2013). With respect to home as a process, we analytically distinguish three dimensions of home: the material, social, and personal (Tanner et al., 2008).

The material home consists of the built environment and design and layout. It refers to the space that can be measured and that gains meaning through its function, culture and history (Sixsmith and Sixsmith 1991). The material dimension of home links to the description of home-making as an embodied process: people experience the home through their bodies (Imrie, 2004; Moore et al., 2013; Schwanen et al., 2012a). The body and embodiment have been prominent subjects of research in geography, especially its relationality with the outside world, in terms of both time and space (Harrison, 2007). This means that the body can never be seen 'on its own', but always in relation to its environment. For instance, a post-stroke body may perform differently in a stroke rehabilitation unit, specialized to cater for its needs, than in the stroke survivor's home. Abrahamsson and Simpson (2011) recently advanced the literature on relationality of the body by introducing the idea of the various 'limits' a body may have. One of the limits they discussed is that of capacity, which means that the – changing-capacities a body has, affect the practices it can perform in place and time. This notion helps us to think about how embodiment is linked with experiences of home.

The outcomes of the interactions between people, their bodies and the material space of the home are the behavioural rituals situated in places, such as getting ready for work in the morning. Such routines have been discussed by Seamon (1980) as "body and place choreographies" (p. 157). When something out of the ordinary happens, people find stability and support in their daily routines, which shows the importance of habit and routine in establishing a sense of comfort and feeling at home. In later work, Bissell (2013) re-established the importance of habit for feeling 'in place' in his study of habits that do not come forth when called upon with skilful golf players in a tournament situation. In the context of ageing, Rowles (2000) argued that unanticipated changes in one's body may occur, that require changes in the home and its routines. At the same time, however, perpetuation of routines can be comforting, in spite of the fact that they become

more difficult to achieve. In such cases, the crux is to achieve a mix of old and new routines, maximizing both autonomy and comfort.

The social home encompasses relationships with significant others who live in as well as visit the home. This includes close relatives such as a partner and children, but also other family members, friends, and neighbours (Tanner et al., 2008). Such a social network may be called upon for emotional support, but also for informal care. In many rapidly ageing (Western) countries, governments, inspired by ever-increasing healthcare expenditures, advocate a 'participation society', where significant others are to provide informal care at home, to sustain their relatives' basic well-being (Foster and Walker, 2014; McNair, 2014; RIVM, 2014). The participation society seems to tie in with Kahn and Antonucci's (1980) convoy model, which is an interdisciplinary model of social relations, focusing on the idea that social relations are rooted in the life course. It argues that individuals are surrounded by supportive people, such as a partner, children, family members, friends and neighbours, over their life course. The relationships with these supportive people vary in their closeness, structure, function and quality, and are influenced by personal and situational characteristics, which change over the life course (Antonucci et al., 2014).

Through its material space, meaningful objects, routines and social relations, the personal home gains meaning as a place of self-expression, as a secure, familiar point in a person's life (Tanner et al., 2008). Thus, our home forms part of our identity. Identity is defined as how we make sense of ourselves, in relation to others, in everyday and local places (Hopkins and Pain, 2007). Identities are constantly re-positioned and re-produced over time and in the socio-spatial context. This pertains especially to processes such as ageing, the physical and social aspects of which require constant re-positioning of the self (Ziegler, 2012). Similarly to identity, the home is also constantly re-positioned in the light of processes such as ageing. In the specific case of stroke, however, survivors abruptly face huge changes in their identity, and struggle to accommodate their changed selves in an unchanged house, which does not feel like home anymore.

3. Methodology¹

To study the stroke survivors' experiences of home, we adopted a qualitative research methodology and conducted 31 semi-structured in-depth interviews with adults who had survived a stroke and experienced moderate to severe post-stroke disabilities. The participants underwent multidisciplinary treatment in a stroke rehabilitation unit for at least one month, and returned home afterwards. The stroke rehabilitation unit is located in a Dutch rehabilitation centre that accommodates different patient groups in specialized rehabilitation departments. All participants received rehabilitation services from a multidisciplinary team of therapists, consisting of psychiatrists, physical, occupational, and speech therapists, nutritionists, psychologists, social workers, movement therapists, and nursing staff. The in-depth interviews were conducted at a location that was convenient for the participants, typically the home. In most interviews, a significant other, often a partner or a sibling, was present during the interview. The characteristics of the participants are summarized in Table 1.

The effects of the stroke as listed for each participant in Table 1 need some further explanation. Physical effects of the stroke typically entail a hemiplegia, which is paralysis and loss of

¹ This study forms part of a previously published larger study. Given that a similar methodology was used, parts of this section are taken from Nanninga et al. (2014).

Table 1
Study participants.

Name	Age	Stroke effects	Marital status	Children (living at home)	House type	Moved	Interview round	Time since stroke onset (months) ^a
John	57	Physical and cognitive	Single	2 (1)	Apartment	Yes	1	10
Paul	50	Physical	Single	2	Row house	No	1	17
Jim	66	Physical and behavioural	Married	2	Row house	No	1	16
Simon	58	Physical and behavioural	Single	2	Apartment	Yes	1	60
Mary	58	Physical, cognitive and behavioural	Single	0	Row house	Yes	1	48
Tom	60	Physical and cognitive	Married	2	Detached	No	1	47
Caren	60	Physical and cognitive	Single	0	Row	No	1	25
Sam	40	Cognitive and behavioural	Cohabiting	1 (1)	Detached	No	1	23
Nina	47	Physical and cognitive	Married	2 (1)	Row	No	1	17
Violet	42	Physical and cognitive	Cohabiting	2 (2)	Row	No	1	23
James	58	Cognitive and behavioural	Married	2 (2)	Row	No	1	7
Victor	71	Physical	Married	2	Apartment	No	1	19
Rose	53	Physical and cognitive	Married	2 (2)	Row	No	1	33
Laura	49	Physical and cognitive	Married	0	Detached	No	1	21
Steven	49	Physical and cognitive	Married	1 (1)	Row	No	1	34
Ben	31	Physical and cognitive	Cohabiting	0	Apartment	Yes	1	36
Marc	68	Physical	Married	2	Row	No	1	71
Daniel	81	Physical	Single	2	Apartment	Yes	1	40
Joan	64	Physical and cognitive	Single	0	Apartment	No	1	77
Sarah	67	Physical, cognitive and behavioural	Married	2	Apartment	Yes	1	49
Bob	63	Cognitive and behavioural	Married	1	Apartment	No	1	34
Isa	48	Physical and cognitive	Single	0	Apartment	Yes	1	78
Linda	72	Physical and behavioural	Single	2 (1)	Apartment	No	1	60
Mike	69	Physical and behavioural	Married	6	Row	No	1	10
Regina	64	Physical and cognitive	Widowed	2	Apartment	Yes	2	10
Kate	61	Physical	Married	5 (1)	Row	No	2	8
Henry	69	Physical	Married	1	Detached	No	2	6
Howard	51	Physical, and cognitive	LAT relationship	1	Row	No	2	6
Raymond	68	Physical	Married	2	Detached	No	2	6
Roy	66	Cognitive	Single	0	Detached	No	2	6
Peter	46	Physical and behavioural	Married	2 (2)	Row	Yes	2	6

^a For the participants who were interviewed in round 2, we recorded the time post-stroke at the time of the second interview.

coordination of one half of the body. Swallowing and speech problems can also be caused by loss of coordination. Cognitive impairments include loss of language, memory, attention, speed of information processing, hemispatial neglect (deficit in awareness of one side of the body and the environment), and apraxia (the inability to perform a series of activities in a sequence or handle objects). These cognitive deficits may in turn influence stroke survivors' behavioural style, in becoming either more slow and cautious, or quick and inquisitive (American Stroke Association, 2015).

Twenty-four participants were interviewed once in 2010 or 2011, between seven months and 6.5 years after the onset of the stroke. They were asked to reflect on their current lives at home and in the community. We also recruited seven participants in 2011 and 2012. They were interviewed twice, once during in-patient rehabilitation in the clinic and once between six and eight months post-stroke. In the first interview, we discussed the participants' expectations about going home, while in the second interview participants were asked to recount their actual post-discharge experiences at home and in the community. Overall, the interview guides covered the same questions; however, our learning experiences and inductive inferences in the first set of interviews were used to refine the questions in the second set of interviews and opened new paths of enquiry. The interviews were conducted by the second author and two research assistants. The first author was present at and observed several interviews. In the second set of interviews, the time since the onset of the stroke was, on average, much shorter than in the first round. However,

we did not find a difference between the home-making experiences between the two groups of participants, neither did we find a pattern in the effect of the time since the onset of the stroke on the participants' home-making process.

To increase our understanding of the social dimension of the home, we also conducted a focus-group discussion with nine partners of stroke survivors. The focus group took place at the rehabilitation stroke unit in 2011. The nine participants, five men and four women, all had a partner who had experienced a stroke one to six years prior to the focus group. The consequences of the stroke varied from moderate to severe impairments. The age of the participants was between 45 and 70 years. Some participants were still working at the moment of the focus group, and/or caring for children living at home, whereas others were pensioned. All partners had rehabilitated at the stroke unit described above, and returned to live at home. The discussion was moderated by a research assistant. The second author was present to take notes, as well as to provide clarification and steer the discussion if necessary. Topics discussed during the focus group discussion included physical adaptations to the home as well as changes that took place with respect to social contacts.

All participants were informed about the aims of the study, signed an informed consent form, and participated voluntarily. The Medical Ethical Review Committee of the University Medical Center Groningen exempted the study from being reviewed. The in-depth interviews and focus group were digitally recorded, transcribed verbatim and coded using Atlas-ti, a software package for qualitative data analysis. In the process of data-analysis, we

combined inductive and deductive coding and analysis (see [Thornberg, 2012](#)). First, we applied a more inductive strategy of analysis, identifying issues raised by the participants themselves which were not necessarily part of the existing theoretical framework on home. This enabled us to identify new themes and patterns. To increase the depth of our analysis of home-making we then applied a more deductive approach by using the material, social and personal dimensions of home as sensitizing concepts, which means they guided the process of data-analysis. As a result, we can build on existing theoretical concepts of home. Coding and analysis were carried out by the first and second authors. The last author reflected on the findings, by reviewing some of the transcripts, the coding and the data-analysis.

4. Findings

We begin our findings by discussing the changes in identity that our participants experienced as a result of the stroke. These help to situate their routines ([Section 4.2](#)) and social relations ([Section 4.3](#)).

4.1. Changed identities and paths in life

Some of our participants managed to come to terms with the post-stroke changes in their identity. Victor, for example, who used to lead an active life, working irregular shifts and travelling a lot after his retirement, together with his wife, accepted and even appreciated that his life was now centering more around the home:

I do enjoy spending time at home. [...] Yes, well, we are done with [travelling]. And we both feel ok with it, yes. [...] We have done a lot, travelled a lot, and I am happy we did all those things. (Victor)

For Victor and his wife, spending more time at home became a next joint step in their personal life history. Although he felt impeded in his daily life because of the stroke – in not being able to use his right hand, having to walk with a walker, and tiring very quickly – the stroke happened during a phase in his life where he was already looking forward to spending more time at home. The stroke may have sped up this process, but the existing anticipation may have facilitated the ease with which Viktor came to terms with his stroke-induced disabilities. Victor's story confirms the insight that in later life, the home may gradually transform from a basis for out-of-home activities to being the locus for every day practices ([Sixsmith et al., 2014](#); [Swenson, 1998](#)). It also relates to the concept of biographical flow in the sense that a stroke and its consequences are seen as something that is part of later life ([Faircloth et al., 2004](#); [2005](#)). Like Victor, around one fifth of our participants had incorporated being 'a stroke survivor' fairly smoothly into their identities. In some cases, such as Victor's, this was related to their phase in life, post-retirement. In others, however, this was related to a lifestyle that already was not very active pre-stroke, which could be continued without much change post-stroke.

The majority of our participants, however, felt they could not incorporate their changed body into their identities, since they abruptly lost the opportunity to engage in activities that were meaningful to them pre-stroke. Their stories show how they struggled to give meaning to their lives at home, such as Simon who went through a divorce, and could not continue his work as a lecturer post-stroke. He explained how the stroke had profoundly changed his sense of home and who he was:

[I feel I] have nothing to offer. [...] I have no work, no partner,

no hobbies [...] not even a stove, and cooking used to be a hobby.... [but] because I can't eat or drink, hardly anyone drops by to visit me. (Simon)

Simon did lose many roles that did define his pre-stroke life: husband, father, academic and cook. For instance, cooking and sharing food with family and friends used to be his hobby, but Simon stopped pursuing this, since he experienced swallowing problems that prevented him from eating and drinking normally. As a result, his home changed from a social place into a lonely one. This relates to [Rowles' \(1983\)](#) notion of autobiographical inside-ness, stressing the link between past, present and future in the ties between people and places. Simon struggled to incorporate the stroke and its consequences in his personal life history. The memories about his meaningful and active pre-stroke life and the huge loss he experienced post-stroke restricted him in recreating a sense of purpose and direction in his life in general, and experiences of home in particular. His series of remembered places clashed with his present personal place. [Bury \(1982\)](#) introduced the concept of 'biographical disruption' for patients with chronic illness. However, the term 'disruption' might be too weak for what Simon experienced through the acute stroke-induced illness. He told us that it was only because of his children that he chose to continue life.

The majority of our participants, both stroke survivors and their partners, struggled to give meaning to their personal homes and lives in relation to who they used and wanted to be, whereas some managed to achieve this rather smoothly, and others with a lot of support from significant others. This does underline the link between the personal home and identity, as well as the nature of identity as being fluid and constantly re-negotiated. The latter has also been argued to be the case for older adults ([Ziegler, 2012](#)). In the rest of our findings, we zoom in to how stroke survivors engage in routines and social relations in the home, in the context of these 'new' identities, that are often still 'torn'.

4.2. Re-negotiating routines at home

As a result of lasting stroke-induced bodily impairments that our participants experienced, the physical and social configuration of their home became difficult to handle, understand and navigate routinely. Almost all participants told us how routine activities of daily life (ADL), such as getting up, having breakfast, and getting a shower, as well as routines in leisure activities in the home, had changed for them. These activities take so much concentration and energy, every day anew, that they can hardly be called 'routine' anymore. For those participants who 'only' experienced physical disabilities, certain behaviours did become re-embodied and taken-for-granted, over time, but at a different level of environmental participation than prior to the stroke. However, the situation was different for participants who – also – suffered from cognitive effects of the stroke. Isa, for instance, told us how taking a shower had become an activity that she needed to plan and lay out carefully. She suffered from apraxia which means she found it difficult to understand the functions of utensils as well as to plan the order of (routine) activities:

In the morning, when taking a shower, you need much more time. But when I just put everything in the right place before I take a shower, I need only 45 minutes for it. [...] I line up what I want to wear in the order I need it, otherwise I put things on in the wrong order, and then you realize and have to start all over. [...] I don't have the overview, I know the order, but when I do not see everything I need, I tend to forget it. (Isa)

Isa's story shows how she had learned to accommodate the demands of her new, apraxic, body, by carefully setting out her

clothes, and planning more time for taking a shower. These stories illustrate the multi-facetness of body and place choreographies of daily routines, as well as what happens when these routines are suddenly disrupted (Seamon, 1980). This confirms the importance of taken for granted bodily routines in the process of home-making, as well as the flexibility they make possible in 'non-disabled' lives. For our participants who suffered both physical and cognitive effects of the stroke, routines potentially changed even more deeply, because for them, it is difficult to combine social routines with routine activities of daily life. This did clash, for instance, with the identities of our female participants with children living at home, since they felt they could not fulfil their former roles as a mother and partner anymore:

V: [As a] mother, [I] used to be able to do ten things at the same time, but I can't anymore. So if my son has something to tell me, I say "[Robert], please, I have to cook dinner first, and then we'll talk later". And they understand [...] They sometimes forget, they just want to share a story and I also understand that.

I: So it's difficult that it doesn't work.

V: Yes, normally I was cooking dinner, doing stuff with my son, talking with my husband, all at the same time. [...] And I just can't do that anymore. (Violet)

Violet's quote illustrates how the bodily effects of the stroke, played out in physical and cognitive impairments, prevented her from being the mother and partner she used to be. This was especially difficult for her, since she felt her family longs for her function again as she used to and to be their mother again. She herself had to remind them that she could not combine all these things simultaneously any more. Because of the hemiplegic effects of the stroke as well as oversensitivity for stimuli and delayed information processing, Violet was not able to combine ADL and social routines anymore, which involved interacting in a fulfilling way with her husband and children while doing household chores. Violet's story illustrates the entwinement of bodily routines, social routines and social roles and relations, and as such the complicated nature of the loss stroke survivors and their families have to deal with upon returning home (Achten et al., 2012; Kitzmüller et al., 2013; Salter et al., 2008).

For many participants, re-establishing old new routines was mainly facilitated by physical adaptations to the house, such as a grab-bar along the stairs. Although this made walking the stairs a bit easier, it remained a challenge to go up- and downstairs. Seven of our participants did move to a new house after having a stroke. Most of them were happy that they had a new house more suited to their physical needs, such as Isa, who moved to a single-floor apartment from a row house with upstairs bedrooms:

This is all even-floored, and the toilet and bathroom are more spacious; because when you look further down the street, [those houses] have a very small bathroom. [...] So here I have more space to manoeuvre. (Isa)

Besides the space, Isa also appreciated there being no stairs, no doorsteps, and less cleaning and maintenance. As a result, it was easier for her to establish new routines, that cost less energy, which enabled her to do other things, such as social activities. In all cases, moving to a new home environment, was not experienced as disrupting, but as enabling. This does contrast with findings in the literature on older adults, where moving is discussed as complex and ambivalent, in which the – feared-loss of the old home, and problems with re-negotiating a new sense of home feature prominently (Löfqvist et al., 2013; Nygren and Iwarsson, 2009; Rowles and Bernard, 2013).

4.3. Interacting with other people at home

Socially, the homes of our participants also often changed fundamentally. Mary, who had become much more sensitive to stimuli and suffered from fatigue, discussed how she changed the social dimension of her home to accommodate her post-stroke self. She contrasted her 'safe' home with spaces outside, which she experienced as tiring.

Everything wears me out, but as soon as I'm [at home], it's fine. It's weird, but as soon as I go outside, everything takes so much energy. Having a normal conversation can be dead tiring [...]. It's the constant effort, so I ended up socially isolated. I want to do it, but I can't. [...] I don't invite friends, because I need to take into account my own fatigue, planning, and how I feel. Yes, there's hardly anything left. [...] I avoid busy places, yes [I go to] the places where I am comfortable, that I know well, the quiet places, but to go into town, no. I can't cope with all the stimuli. I can do the shopping mall, but I need to be really fit to manage that, so I go there on my day off, usually Wednesday afternoon. (Mary)

Mary, being single, had managed to recreate her home according to her post-stroke needs by not inviting friends anymore, although this resulted in her becoming socially isolated against her will. She thereby had to give up not only her home as a place for strengthening important relationships, but also part of her pre-stroke identity as a sociable person and a good friend. Mary's story thus shows that the home can become both a refuge and a place where stroke survivors feel locked up against their will at the same time. Similar tensions were reported by most of our participants. This reveals that the process of homemaking of stroke survivors is often full of tensions, an insight which may deepen theoretical insights in home-making, in the rehabilitation literature in particular (Mayo et al., 2000; Struhkamp et al., 2009; Wood et al., 2010). When looking at those participants who did not live alone, we observed they typically became more dependent on their partners. In some cases, such as Sarah's, this was discussed as a natural process of relating differently to each other:

I: Did your relationship change because of the stroke?

P: It may have become more intense, since we need to take each other's needs into account.

S: We rely more on each other.

P: She has lost her independence, which has led to us relating differently to each other. (Sarah and partner)

Sarah and her husband told us how their relationship had improved after the stroke. Her husband had found a new experience of home and personal growth in providing informal care to his wife. However, this was a rare case, since many partners resented how their home had become a place of giving and receiving informal care. This excerpt from the focus group interview with family caregivers is illustrative in this respect:

"M: I am still married, but I don't have a wife, in terms of continuing the relationship we used to have. That's over [She did not recognise me as her husband]. I remained 'he' for a long time, when something needed to be taken care of. I wasn't [Martin] for her. I was a stranger. And although she might have had the faintest awareness that I would be her husband, she could not express that. Really difficult [...]

J: Yes, you have to give up a lot. Did you get help to deal with this?

E: No. Although that's very important. I don't know whether you also experienced it like that, but I thought I could handle it all. [group approves]. And I collapsed after two years. I couldn't

do it anymore, nobody can. I could never do things the right way.

G: No appreciation.

E: Indeed, and suspicion, my husband is so suspicious, he asks me why I do stuff with everything I do, he keeps making demands on me, and that wears me out. That you can't even take a breath without the other, that's very difficult.

Several family caregivers said they felt they had to care for another child, and that their partners had become strangers for them (and the other way around). This fact made assisting with ADL and especially dealing with behavioural changes in their beloved very demanding. These caregiving experiences dramatically changed both the social home in terms of roles and relationships and the identities of family caregivers. This does confirm findings in the literature on caregiving experiences, such as by Hammarström and Torres (2010), Milligan (2005), Milligan and Wiles (2010) and Sixsmith et al. (2014). Although caregivers' experiences were not the focus of our study, our findings seem to capture a more negative experience of caregiving than that articulated in other studies.

In many cases, the challenge of coping with the situation was increased by the fact that other people in the social network tended to refrain from providing the much needed support and understanding. James and his partner, for instance, felt that the people in their social network let them down: at first, family, friends and colleagues would come to visit and showed empathy, but this decreased over time.

P: I can count the people who remain, whom we can rely on, on the fingers of one hand. [...]

J: They figured, well he's on his feet again, he's alright. [...] They don't understand. Do you need to show the outside world all the time how you've been hit? So if you look 'normal' but have changed inside, what about that? [...] Since it does not show, it's like, oh, that's not too bad, wow, you're cycling, too? (James and partner)

Both James and his wife told us that their social network now encompassed only their children and a couple of close friends, and most other participants recounted similar experiences. James and his wife felt this happened because people could not understand the invisible, cognitive and emotional effects of the stroke: James' body did still look the same on the outside, but its inside had changed, and he felt that other people did not interacted properly with his, seemingly recovered, post-stroke body. Our single participants expressed similar experiences, which affected them even more, since they did not have a partner to rely upon in everyday life. Overall, the composition of our participants' social relationships, in terms of closeness, quality, function and structure, not only changed but also decreased drastically (Antonucci et al., 2014), and against the will and control of stroke survivors and their partners. This contradicts Rowles' (1983) work on older adults in the United States in which he discussed how older adults engage with other people, to become part of the social order of a place. Our findings confirm that support from a larger social network is important when (re)negotiating the social meaning of home (Antonsich, 2010; Shin, 2014). Social support may prevent stroke survivors, their partners, and their children from becoming socially isolated.

5. Conclusions

Our study focused on adults who survived a moderate to severe stroke and returned to home with lasting disabilities after discharge from a stroke rehabilitation unit. We found that since the

bodies of stroke survivors suddenly become limited in terms of capacity, their experiences of home, over time, and in relation to both other people and the material environment are affected. Thus, we conclude that 'home' is an emergent outcome of bodily being-in-the-world, full of ambiguity and replete with tensions, rather than a pre-given. This confirms findings from the literature on home, that when the "choreography of being in place" (Rowles, 2000: 59 S) is disrupted there is a diminution of self and a loss of identity and relationship to place and community. Our participants had to redefine both their identities and their homes to solve the incongruences between pre- and post-stroke, and most of them struggled at this. Similarly, Price et al. (2012) showed that it often takes a lot of time and energy to abandon the previously anticipated life course, and to develop an alternative projected life course that is acceptable and satisfying (Price et al., 2012).

We showed that routines and social relations have the potential to provide a renewed sense of stability to home-experiences. Many participants had lost the inherent bodily awareness of the physical aspects of their home environment: those with coordination problems in the time and effort it takes to move from one place to another and conduct routine daily activities such as shaving, dressing and cooking, and those with perception problems such as apraxia and neglect in terms of literally losing their way in routine activities, in information, and at 'familiar' places. Furthermore, individuals' pre-stroke social routines were also effected, and needed to be adjusted by carefully planning or cancelling them, to recreate a sense of home. This also impacted the identities and homes of our participants' partners and sometimes children, who often became informal care-givers. This calls for more in-depth research, especially on the experiences and emotions of (informal) care-givers in the home setting.

Our findings carry several implications for stroke rehabilitation. Firstly, that it is important to develop interventions that help to strengthen the homemaking process of stroke survivors and their families in all its complexity. Our study increased the understanding that modifications to the physical house are just a preliminary step in the home-making process. Re-creating built-in bodily and social routines, that create stability and control, is necessary to re-develop a sense of home. The key question is how to shift conceptualizations and related stories of home from the context of cultural geography and geographical gerontology, including the findings of our case study, to that of rehabilitation medicine in general and neurological rehabilitation in particular, thus how to transform, to translate and to put it in action in the field of rehabilitation practice and stroke care.

Another implication for the field of rehabilitation practice, stems from the enormous diversity in the experiences of our participants, with regard to re-positioning and re-producing their homes and identities. Factors such as the precise effect of the stroke, coping strategies, gender, age, pre-stroke roles, lifestyle and personality, as well as a stroke survivor's social network and home-environment all effect both each other and the process of home-making. Therefore, we conclude that re-producing a sense of home post-stroke is a highly individualised practice. This does provide a case for providing person-centered support and care, that is tailored to the needs of individual stroke survivors and their families (see Lund et al., 2012).

In our study, we asked survivors and their family caregivers to talk about their experiences and feelings, for instance how stroke as an illness effected their home place. By focusing on the embodied experiences of stroke survivors we chose to take a phenomenological stance in our study, as has been done recently by others such as Antoninetti and Garrett (2012), Schwanen et al. (2012b) and Ziegler (2012). However, an important area for future research entails how home making is *done* at different places post-stroke, through methods such as (participant) observation and go-along-

interviews. Such methods will foreground the practices through which materialities such as staircases, doorbells, kitchens, paralyzed limbs, food, leaflets, intake or measurement tools are handled. Inspired by material semiotics and Actor Network Theory, such materialities will then be imagined as active agents that come into being – and disappear – with the practices through which they are played out and manipulated (Law and Mol, 2002; Mol, 2002; 2008). Such an approach would contribute to current theoretical debates in material geographies and Non-Representational Theory on the one hand (Cook and Tolia-Kelly, 2010; Simpson, 2013), and to knowledge practices in the field of rehabilitation on the other (Lettinga and Mol, 1999). This will further the insight that the quality of stroke rehabilitation is not only to work against loss, but also to bear it.

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